

**New Hampshire Department of Health and Human Services
The New Hampshire Family Caregiver Support Program &
Alzheimer's Disease and Related Disorders**



The New Hampshire Family Caregiver Support Program & Alzheimer's Disease and Related Disorders

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Program Operations Guide for the
ServiceLink Aging and Disability Resource Centers





The New Hampshire Family Caregiver Support Program & Alzheimer's Disease and Related Disorders

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The New Hampshire Family Caregiver Support Program & Alzheimer's Disease and Related Disorders

Program Guide

The History of the New Hampshire Family Caregiver Support Program

The New Hampshire Family Caregiver Support Program was established as a result of the Older Americans Act Amendments of 2000, Older Americans Act, as amended, Public Law 106- 501, Title III, Part E, which established the National Family Caregiver Support Program funded by the Federal Administration on Aging.

Through this program, administered by the New Hampshire Bureau of Elderly and Adult Services, limited funds are available for short-term respite care to enable full time, unpaid family caregivers to be temporarily relieved from their caregiving responsibilities. In addition, limited funds are available for supplemental services to complement the care provided by the family caregiver.

In 2006, the Reauthorization of the Older Americans act ushered in major changes offering services to a wider group of family and kinship caregivers under the National Family Caregiver Support Program. New priority guidelines were also issued under this reauthorization.

The Modernization of the Older Americans Act of 2006 ushered in the following changes to the National Family Caregiver Support Program

The Administration on Aging (AOA), in partnership with the Center for Medicare/Medicaid Services (CMS), designed the Aging and Disability Resource Centers (ADRCs), now operational in 43 States and territories, to provide consumers and caregivers information on home and community-based long-term care services. The ADRCs known as the ServiceLink network in New Hampshire, provide for consumers information, options counseling, referral, assessment, education and assistance in planning for future needs. AoA is emphasizing the importance of integration of proven evidence-based health promotion interventions, which can lessen disability related to chronic illnesses, prevent falls, and reduce the burden experienced by family caregivers of individuals who are older and/or disabled.

For individuals with a high-risk for nursing home placement, funds can be used by States to target these low and moderate-income individuals and their caregivers who may be better served through home and community-based services. Through a variety of consumer-directed options, such consumers may select their own providers and direct how their services will be delivered.

As a result of the Reauthorization of the Older Americans Act in 2006, eligibility changes were made to the National Family Caregiver Support Program. The eligibility changes included:

- Family caregivers of a person with Alzheimer's disease or a related dementia may be served regardless of the age of the person with dementia.



- Grandparents and other relative caregivers providing care to children (under age 18 years) may receive services at 55 years of age and older (previously it was 60 or older);
- Grandparent or relative caregivers, providing care for adult children with a disability, who are between 19 and 59 years of age, can be served under the NFCSP as follows:
 - Caregivers must be age 55 years and older (cannot be parent or step-parent of adult child);
 - Priority is given to caregivers providing care for an adult child with severe disabilities; and
 - Exception: Older caregivers providing care to their adult children with disabilities can be served in the NFCSP if the adult children are 60 years of age and older.

Note: No more than 10% of Title III-E funds may be utilized for support services for caregivers serving children under age 18. Services provided to caregivers of adult children are not counted against the 10% ceiling for grandparents or other relative caregivers of children under the age of 18.

The Purpose of the Program and How it Works

Families are the major provider of long-term care, but research has shown that caregiving exacts a heavy emotional, physical and financial toll. Many caregivers who work and provide care experience conflicts between these responsibilities. Twenty two percent of caregivers are assisting two individuals, while eight percent are caring for three or more. Almost half of all caregivers are over age 50, making them more vulnerable to a decline in their own health, and one-third describe their own health as fair to poor.

The NFCSP offers a range of services to support family caregivers. Under this program five types of services will be provided:

- information to caregivers about available services,
- assistance to caregivers in gaining access to the services,
- individual counseling, organization of support groups, and caregiver training,
- respite care, and
- supplemental services, on a limited basis



These services work in conjunction with other State and Community-Based Services to provide a coordinated set of supports. Studies have shown that these services can reduce caregiver depression, anxiety, and stress and enable them to provide care longer, thereby avoiding or delaying the need for costly institutional care.

Eligible Program Participants

While the Aging Network has always been involved with meeting the needs of both care recipients and family caregivers, by creating the National Family Caregiver Support Program, Congress



explicitly recognized the important role that family caregivers occupy in our nation's long-term services and supports system. As of the 2006 Reauthorization of the Older Americans Act, the following specific populations of family caregivers are eligible to receive services:

- Adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older;
- Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer's disease and related disorders;
- Grandparents and other relatives 55 years of age and older providing care to children under the age of 18; and
- Grandparents and other relatives 55 years of age and older providing care to adults age 18-59 with disabilities.

- Effective July 2016, parents of adult child 18 years and older with disability are eligible

Each family caregiver presents his or her own unique needs and preferences for the types of programs and services they wish to receive at any given point in time.

Authorizing Statutes- National

PART E—NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

http://www.aoa.gov/aoa_programs/hcltc/caregiver/index.aspx

Authorizing Legislation: Section 371 of the Older Americans Act of 1965, as amended

Target Population as defined by the Administration on Aging

Family Caregiver Definition Sec. 302(a)(3) - The term 'family caregiver' means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction.

Grandparent or Older Individual Who is a Relative Caregiver Sec. 372 - "Grandparent or relative caregiver" includes those 55 years of age or older caring for a child to whom they are related by blood, marriage or adoption. The term "grandparent or older individual who is a relative caregiver" means a grandparent or step-grandparent of a child, or a relative of a child by blood, marriage, or adoption who is 55 years of age or older and; (A) lives with the child; (B) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and (C) has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally.

Child Sec. 372 - The term "child" means an individual who is not more than 18 years of age or who is an individual with a disability.

Priority Considerations Sec. 372 (b)



Give priority in service provision to:

Family caregivers who provide care for older individuals with Alzheimer's disease and related disorders with neurological and organic brain dysfunction.

Grandparents or relative caregivers caring for children with severe disabilities.

Low-income older individuals, including low-income minority older individuals, older individuals with limited English proficiency, and older individuals residing in rural areas.

Support Services Sec. 373

The NFCSP provides for a multifaceted system of support services for family caregivers; and for grandparents or older individuals who are relative caregivers.

The services provided, in a State program under subsection (a), by an area agency on aging, or entity that such agency has contracted with, shall include:

- (1) **Information** to caregivers about available services;
- (2) **Assistance** to caregivers in gaining access to the services;
- (3) **Individual counseling, organization of support groups, and caregiver training** to assist the caregivers in the areas of health, nutrition, and financial literacy, and in making decisions and solving problems relating to their caregiving roles;
- (4) **Respite care** to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- (5) **Supplemental services**, on a limited basis, to complement the care provided by caregivers.

MAINTENANCE OF EFFORT Sec. 374

Funds made available under this subpart shall supplement, and not supplant, any Federal, State, or local funds expended by a State or unit of general purpose local government (including an area agency on aging) to provide services described in section 373.

Consumer Contributions Summary Sec. 315

Such contributions shall be encouraged for individuals whose self-declared income is at or above 185 percent of the poverty line, at contribution levels based on the actual cost of services. Voluntary contributions can be solicited for participants based on self-declaration of income. This includes older individuals with limited English proficiency and to supplement (not supplant) funds received under this Act.

Authorizing New Hampshire State Statute

https://www.lawserver.com/law/state/new-hampshire/nh-statutes/new_hampshire_revised_statutes_chapter_161-f



TITLE XII PUBLIC SAFETY AND WELFARE CHAPTER 161-F: 76 – 80

Caregiver Support Services

Section 161-F: 76

161-F: 76 Purpose. – Over 80 percent of long-term care services are provided by unpaid family caregivers. It is in the state's best interest to support these caregivers to maintain their family member at home. The purpose of this chapter is to provide support to these caregivers in their role as primary caregivers for aging family members. *[Source. 2010, 81:1, eff. July 18, 2010.]*

Section 161-F: 77

161-F: 77 Definitions. – In this subdivision:

I. "Caregiver support services" includes, but is not limited to, assessment, individual and caregiver centered planning and assistance, information and referral, respite care, caregiver support groups, educational materials, and emergency and outreach services.

II. "ServiceLink Resource Center" or "SLRC" means the statewide network of locally administered community-based resources for seniors, adults with disabilities, and their families.

[Source. 2010, 81:1, eff. July 18, 2010.]

Section 161-F: 78

161-F: 78 Administration; Services. – Subject to available federal, state, and local funding, the department shall administer this subdivision and shall coordinate caregiver support services with existing services to caregivers and older adults. Caregiver support services shall be provided in a manner which develops person-centered, comprehensive, responsive, and flexible support to caregivers in their role as the primary caregivers for aging family members.

[Source. 2010, 81:1, eff. July 18, 2010.]

Section 161-F: 79

161-F: 79 Regional Caregiver Support Services. – The department shall maintain a caregiver support program in each SLRC. A caregiver support specialist shall be available within each SLRC region to assist caregivers in assessing their needs and accessing support and services; including generic community resources, state and federally funded support services, and other services as available. *[Source. 2010, 81:1, eff. July 18, 2010.]*

Section 161-F: 80

161-F: 80 Rulemaking. – The commissioner shall adopt rules under RSA 541-A relative to:

- I. Further definition of services to be provided under this subdivision.
- II. Requirements for eligibility for services.
- III. Manner of providing services under RSA 161-F: 78.
- IV. Assignment and roles of caregiver support specialists pursuant to RSA 161-F: 79.

[Source. 2010, 81:1, eff. July 18, 2010.]

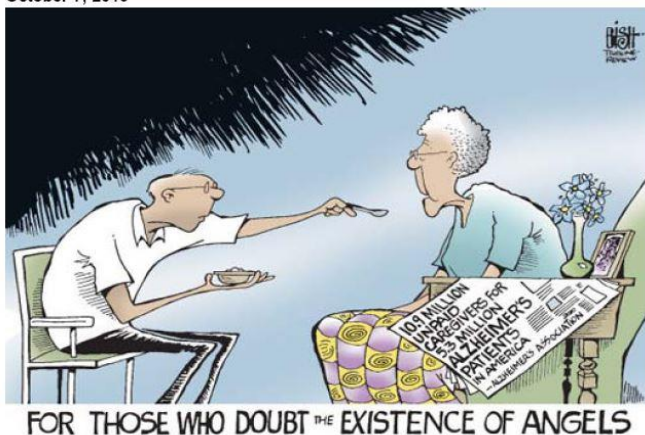


The Alzheimer's Disease and Related Disorders Program

Background

The Alzheimer's disease and Related Disorders Program (ADRD) was written into New Hampshire state statutes in 1989 and provided for respite care services for individuals with a diagnosis of Alzheimer's disease or other related disorders. These services are funded by State General Funds.

October 7, 2010



Political Cartoon: "The Existence of Angels" by Randy Bish, Pittsburgh Tribune-Review, October 7, 2010

Alzheimer's Disease and Related Disorders

161-F: 65 Statement of Purpose. – The general court finds that Alzheimer's disease and related disorders (ADRD) affect an alarmingly high percentage of citizens and that ADRD creates a great strain on the families of victims of the disease. In enacting this subdivision, it is the intent of the general court to address these concerns and to promote public awareness of ADRD. [Source. 1989, 7:1, eff. Jan. 1, 1990.]

161-F: 66 Definitions. – In this subdivision:

- I. "ADRD", Alzheimer's disease and related disorders, means a condition which receives a differential diagnosis of Alzheimer's disease or a similar irreversible dementia.
- II. "Eligible person" means any adult who is unable to attend to his daily needs without the assistance or regular supervision of a primary caregiver due to ADRD.
- III. "Primary caregiver" means the family member or other natural person who normally provides the home care and supervision of a victim of ADRD.
- IV. "Respite care service" means care provided on an intermittent basis to the eligible person to relieve the primary caregiver from the demands of home care for a limited period of time. [Source. 1989, 7:1, eff. Jan. 1, 1990.]

161-F: 67 Respite Care Service Established. – The commissioner shall establish and administer a statewide respite care service for the purpose of providing respite care for eligible persons by trained respite care providers. The service shall be purchased through contracts, and



to the extent feasible shall be coordinated through local agencies. [Source. 1989, 7:1. 1995, 310:183, eff. Nov. 1, 1995.]

161-F: 68 Guidelines; Fees Established by Rules. – Respite care service may be on a planned or emergency basis either in the home of the eligible person, in an out-of-home respite care setting, or in a licensed nursing home. The commissioner shall adopt rules pursuant to RSA 541-A, relative to appropriate fees for respite care services. [Source. 1989, 7:1. 1991, 128:1. 1995, 310:115, eff. Nov. 1, 1995.]

. 1989, 7:1. 1991, 128:2, 3. 1995, 310:116, eff. Nov. 1, 1995.]

Background

Prior to 2011 the Alzheimer's Disease and Related Disorders funds for respite care services were contracted out to community VNA or home health agencies to administer. Although no rates were set for the services, agencies could charge administrative fees at their discretion and broker fees should the family caregiver choose a different agency to provide services other than the contracted agency.

With the advent of consumer-directed services in the NH Family Caregiver Support Program the ADRD funds were rolled into that same model. As a result, family caregivers had more choice and control over the funds they received for respite care. In addition, the ServiceLink sites had the option of providing supplemental services under Title III-E and respite care services utilizing the ADRD funds. One on one counseling, regular check-ins, access to a variety of options in terms of local services and different funding sources provided a broader range of services and supports for family caregivers caring for an individual with ADRD.

Unfortunately after a difficult budgeting season the ADRD funds were suspended from the State budget for SFY12 and SFY13. The suspension of the funds happened to coincide with the adoption of the rule revision for Alzheimer's Disease and Related Disorders (He-E 503). The revised rule changed the administration of the funds and the process to consumer-directed services, and raised the annual cap to \$1500 from \$1200.

Definition of terms

Action Steps Plan – A plan outlining the steps identified in the Options Counseling process that are needed by the individual and/or counselor to attain supports that meet the goals and preferences of the individual. This plan is time-limited and is directed and developed by the individual with support from the Options Counselor as needed. A copy of the action steps plan may be kept by both the Options

Counselor and the individual as both may have action items to complete, and it may serve as a guide for the Options Counselor in following up with the individual as well. The action steps plan is the deliverable after OC process is complete. It outlines the steps individual will take to address the presenting goal or intention. It is driven by the individual and for the individual.

Activities of Daily Living (ADLs) – is a term used in healthcare to refer to daily self-care activities. Health professionals routinely refer to the ability or inability to perform ADLs as a measurement of the functional status of a person, particularly in regards to people with disabilities and the elderly. ADLs consist of self-care tasks, including:



- A. Personal Hygiene and Grooming
- B. Dressing and Undressing
- C. Self- Feeding;
- D. Functional Transfers (getting into and out of bed or wheelchair, getting onto or off toilet, etc.);
- E. Toileting (bowel and bladder management)
- F. Mobility (ambulation, walking without use of an assistive device such as a walker, cane, or using a wheelchair)

Instrumental Activities of Daily Living (IADLs) are activities related to independent living and involve interaction with the physical and social environment, including

- A. Meal Preparation: Care recipient can prepare breakfast and light meals
- B. Telephone: Can use telephone as necessary, e.g., able to contact people in an emergency
- C. Light Housework: can do light housework; washing dishes, dusting (daily basis), making bed
- D. Managing Finances: Can manage own finances; banking; handling checkbook; paying bill
- E. Medication: Can take medication on time with correct dose, without assistance
- F. Transportation: Needs transportation and/or escort to medical, dental appointments, necessary engagements, or other activities or needs

Consumer-direction or Self-direction is an approach to providing services (including programs, benefits and supports, and technology) intended to assist the individual so that:

(A) Services (including the amount, duration, scope, provider, and location of the services are planned, budgeted, and purchased under the control of the individual;

(B) The individual is provided with the information and assistance necessary and appropriate to enable the individual to make informed decisions about the individual's care options;

(C) The needs, capabilities, and preferences of the individual with respect to services, and the individual's ability to direct and control the individual's receipt of services, are assessed by the ServiceLink sites involved;

(D) Based on the assessment made by the ServiceLink staff, both the SLRC staff together with the family caregiver (and/or legal representative if appropriate) develops a plan of services for the individual that specifies which services the individual will be responsible for directing services under the plan; utilization of the budget for the services and determining the role of family members (and others whose participation is sought by the family caregiver.

(E) The ServiceLink staff provides for oversight of the family caregiver's self-directed receipt of services, and the appropriate use of funds.



Decision Support – Decision support involves a process of examining the pros and cons of various options. It may include information and education, but goes beyond both of these to support an individual as he or she weighs options.



Family Caregiver or Informal Caregiver are terms used to refer to unpaid individuals such as family members, partners, friends and neighbors who provide care. (Formal caregivers are volunteers or paid care providers associated with a service system.)

Long-Term Services and Supports (LTSS) – Services and supports that promote independent living by providing support with Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) or any other support that enables an individual to live independently in the community.

Options Counseling - Options Counseling is a person-centered, interactive, decision-support process whereby individuals are supported in their deliberations to make informed long-term support choices in the context of their own preferences, strengths, and values. The process may include developing action steps toward a goal and, when requested, assistance in accessing support options. It also includes following-up with the individual. Options Counseling is available to all persons regardless of their income or financial assets. In some cases, caregivers may be the individuals seeking assistance with decision making. Options Counseling should be offered to caregivers to assist in determining their desire for caregiver support which might include: communication strategies, ways to reduce caregiver stress, and the importance of individual self-determination.

Person-Centered Planning (PCP) – A process to develop an individualized support plan that is driven by an individual's own preferences, strengths and personal goals as well as directed by the participant and/or their representative.

Participant-Directed Services (see Consumer-direction or Self-Direction) – Publically funded long term support services that are planned, budgeted and directly controlled by an individual (with help of representatives, if desired) based on the individual's preferences, strengths, and needs.

Respite is defined as an "interval of rest or relief." Respite is necessary for individuals who are providing long term care to a family member, partner or friend. The stress of day-to-day care and multiple demands on their time takes its toll over the long run. Although taking on this role does have its rewards, it also can be frustrating, challenging, lonely and sometimes overwhelming. It is important that caregivers get a break now and then to take care of themselves and their own needs. A change of activities and surroundings can prevent burnout and emotional or physical exhaustion. Planned or occasional breaks can help the family caregiver step out of the role for respite a while, relax, and return to the situation with renewed energy.

Respite grant funds are NOT intended to provide services to the care recipient so that the caregiver can work.



Essential Services

The NHFCSP funded by the AoA, utilizes a consumer-directed model. Through assistance from ServiceLink Resource Centers (hereafter “SLRC”) staff, family members and others who provide care for an elderly adult, or grandparents and relatives raising a child or children, or an adult child with disabilities can gain needed help. Regardless of where family caregivers are in their caregiving role, whether they are a long distance caregiver, or just starting to provide assistance, or have progressed to full time care, assistance is available (see chart below). Families and others play a critical role in enabling seniors to remain in their own homes for as long as possible.

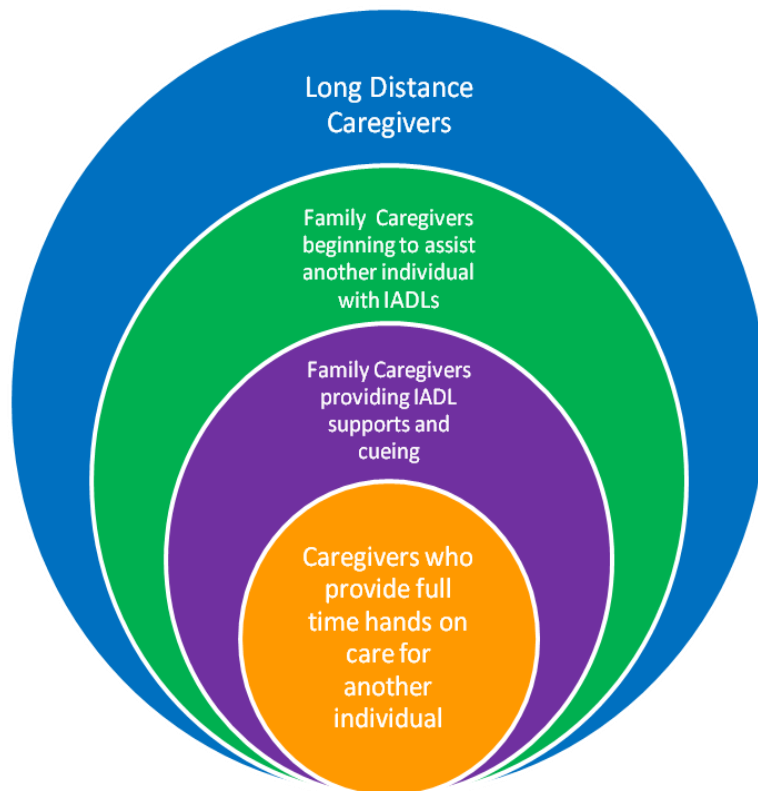
This chart roughly illustrates the caregiving trajectory. The level of care the family caregiver is providing often determines the level of assistance needed.

For example a long distance caregiver could benefit from information on what services are available for their family member. Family members and others who are beginning to assist another individual with tasks such as making appointments, driving them places, helping them to keep track of their finances, etc. could be helped with some levels of assistance such as homemaker services or meals. This may be a good time to bring up (if they haven’t done so already), talking with their family member about planning ahead.

Family caregivers who are providing a high level of IADL support and cueing could require much more assistance. Many of them may be caring for a family member with Alzheimer’s or dementia. These two groups would be the ones that would fall into the eligibility category for respite care services.

Information Services

A follow up call is made after a referral, to see how the referral worked out, providing an additional opportunity to answer questions, offer information, or connect people with needed services which ultimately makes caregivers feel empowered and more satisfied with their individual circumstances.





Access Assistance

Access assistance is getting caregivers connected with needed supports and services. At times the staff may assist the caregiver in making connections by placing phone calls to agencies and providers on their behalf. Follow up is important to see if the connection(s) were successful for the caregiver.

One on One Counseling, Support and Options Counseling

Decision support is one of the key elements that distinguish Options Counseling from Information and Referral, and Access Assistance. Caregiver Specialists take time to get to know the caregiver, build rapport, and understand and take individual circumstances into account when providing information, assistance, and options counseling.

The Caregiver Specialists apply the individual's special circumstances and needs when helping customers weigh the pros and cons. One person's pros and cons may not be another's. (If staff are having the same conversation with everyone, they are not personalizing information.) This can lead customers to feel disempowered and their individual needs may not be met. Narrowing down resources and information in response to the individual's special circumstances and pros and cons is an important service that ServiceLink staff can provide. Information is tailored and caregivers are given time to think about and explore all their choices before making decisions.

Essential components of Options Counseling include:

- a person-centered interview,
- identification of desired and available options (including personal, public, and private resources),
- a facilitated decision-support process (weighing pros/cons of various options),
- assistance, as requested, to develop an action steps plan that is directed by the individual,
- connections to services and supports when requested, and
- follow-up.

Person-Centered Interview (Conversation)

A key component of effective options counseling is a person-centered dialogue to learn about the person's values, strengths, preferences, and concerns. This discussion is a process of discovering factors important to the individual to assist the person in exploring options and developing an action steps plan. ServiceLink staff assist caregivers to be empowered to gather information, find resources, and makes decisions; the caregiver is the center of this process.

- This conversation may occur once or over a series of interactions.
- The conversation should touch on key areas that would influence available options relevant to the individual's situation including strengths, physical, emotional, social, financial, and functional aspects. Based on the ServiceLink model of options counseling,



the ServiceLink staff (Options Counselor) may need to obtain specific, pertinent information to assist in applying for publically funded services and supports.

- The conversation should occur in a timely manner and meet the schedule and needs of the individual. A tailored list of needs and resources that the individual identifies as helpful for him or her should be made available to them in a timeframe that gets the information to them when they need it to make decisions.
- Options Counseling is person-centered and the individual controls the planning process, which includes: selection of goals; when and where meetings are held; who is a part of the planning meetings; the topics to be/not to be discussed; and personal decisions about supports and services.

Exploring Options/Planning

Options Counseling includes the exploration of resources so that family caregivers can choose what is right for them. This would include current and anticipated future long term services and supports. Resources may include informal support, privately funded services, publically funded services and benefits, among others.

- OC should include discussion of available options without the personal bias of the Options Counselor.
- Organizations providing OC should not have a vested interest in decisions made by individuals.
- As part of the OC process, the options counselor will encourage the individual to explore informal supports that might be available such as support from community groups, places of worship, neighbors, and friends.
- The OC process will include discussion of publically funded services as well as private services including the approximate cost of services.
- Options Counselors may also facilitate futures planning by talking with individuals about options for services and supports should they be needed in the future.
- To assist in the exploration of available options, it is recommended that Options Counselors assist individuals, when necessary, in making appropriate connections to persons that have specific training in available benefits and expertise related to the persons options (such as SHIP counselors, financial, employment, mobility assistance, etc.)

Decision Support

In addition to discussing and sharing information about available resources, Options Counseling assists the person in evaluating various pathways, including the pros/cons of specific options. This is one of the key elements that distinguish options counseling from Information and Referral, and Access Assistance.

Decision support is best performed by utilizing specific decision support tools, decision support processes, and decision support techniques, such as motivational interviewing and person



centered planning, and person-centered tools such as those presented in *Methods, Models and Tools* training.

Collaboration with Individual to Develop Action Steps

Another component of the options counseling process is offering to assist the person in developing his or her personal written plan of action. The written plan serves as a guide for the individual for future work and/or steps necessary to achieve goals that are important to the person.

The best written plans are developed to the greatest extent possible by the individual with assistance as necessary. It is important for the plan to be shared by the individual with others as desired, as well as retained in a file or electronically by the Options Counselor to use in following up.

Access to Community Supports

In addition decision support, Options Counselors will also provide assistance as requested by the individual to access chosen services and supports.

Follow-up

Follow-up is an essential component of Options Counseling to be offered to each individual. At this point the Options Counselor learns from the individual what progress towards goals and steps in the action plan has occurred. Any barriers to implementing the action plan can be discussed and the Options Counselor and individual can strategize about alternatives.

Consumer-Directed Respite and Supplemental Services

The ServiceLink sites work one on one with family caregivers and have been designated by BEAS to have the spending authority over the budgets that they allocate to eligible individuals.

Developing Budgets for Services

For those who are eligible for and are authorized a budget for services the following are things to consider when assisting family caregivers in developing their budget.

When working with family caregivers on a budget for services please keep in mind these funds are to be the payer of last resort. Does the family have means to pay for services? Sometimes sites choose to offer a small amount of funds for caregivers with means to try respite. Recognizing the value of it is sometimes enough for them to pay for respite themselves.

Allowable Expenditures for III-E Budgets

Respite Care for Caregivers of Older Adults

Respite care can include:

- a family member, friend or relative (who does not live in the same household) hired under an agency or the FMS provider to provide respite care services; or
- a home health agency;



- adult day program; or
- a facility for short term respite;
- personal care;
- homemaker services; or
- companion care

Impromptu Respite

The purpose of “impromptu” respite on the budget worksheet is for emergency situation where the caregiver needs to run out and asks someone to cover for them while they are out and wants to pay that individual for their time. The amount cannot be more than 10% of the caregiver’s overall budget. For instance if the caregiver’s budget for services is \$600, the “impromptu” expenditures for respite cannot exceed \$60. Some caregivers may use this if they want to try out a worker before committing to them.

Please keep in mind that respite care services are for the primary benefit of the caregiver and should provide them with an adequate break. The services should not be for the sole benefit of the person receiving the care. The services should benefit both.

Respite Care for Grandparent and Relative Caregivers

Respite care can include:

- a family member, friend or relative (who does not live in the same household) hired under an agency or the FMS provider to provide respite care services; or
- day camp or overnight camp (limited basis)
- after school activities
- occasional child care

Supplemental Services for Caregivers of Older Adults

Supplemental Services are services on a limited basis (**up to \$1000.**) that complement the care the caregiver is providing. Allowable services include:

- snow plowing;
- yard work for safety reasons;
- heavy cleaning;
- assistive and adaptive devices;
- personal emergency response systems
- Transportation to and from adult day and/or to and from medical appointment)



- incontinence supplies (depends, chucks, powders and creams related to incontinence)
- nutritional supplements such as ensure

Supplemental Services for Grandparent and Relative Caregivers

Supplemental Services are services on a limited basis that complement the care the caregiver is providing. Allowable services include:

- snow plowing;
- yard work for safety reasons;
- heavy cleaning;
- Transportation to and from camp
- assistive and adaptive devices;
- necessary school supplies that could not be obtained elsewhere
- clothing

Note: No more than 25% of the site's budget for III-E services for caregivers can be used for supplemental services. For example: if a site has \$10,000 for the year to authorize services for family caregivers, no more than \$2,500 can be authorized for supplemental services.

Be creative- Though ensure you stay within the guidelines. If you have questions, talk it out with the program staff BEAS Family Caregiver Manager before authorizing it.

Expenditures that Would Not be Allowable

Title III-E funds in New Hampshire cannot be used for:

- medical treatments
- prescription drugs
- co-pays for services
- medically necessary devices that could be paid for under Medicaid or Medicare
- in/out shower or personal care appointments solely for the benefit of the care recipient
- to pay for services funded by another program or funding source
 - respite care under Choices for Independence Program
 - respite care provided by the VA Medical Centers and/or through VD-HCBS
 - services and devices paid under VA, Medicaid , Medicare, or private insurance
 - other funding sources such as Title XX



- Goods or services that are not related to caregiving
- III-E funds cannot be utilized to pay the cost share or sliding scale fee that the individual is expected to pay for Title III-B funded services. For example: an adult day program may offer III-B funded units for their program but asks for a sliding scale fee of \$10 each day due to the self-reported income level of the family. Title III-E **cannot** be used to pay for this fee.

Alzheimer's Disease and Related Disorders (ADRD) Funds

Funds for respite care services are not means tested, but are limited to family caregivers caring for an individual with diagnosis of Alzheimer's disease or other related disorder. Respite providers, including individuals, are oriented to the care recipient's routine by the caregiver. The annual amount authorized to family caregivers must not exceed \$1500.

Comparison of Eligibility Requirements of Funding Sources:

Family Caregiver III-E	ADRD
Full time caregiver lives with or in close proximity of care recipient. Provides approx. 40 hours week of caregiving support.	Full time caregiver lives with care recipient and provides care 24 hours per day
Unpaid informal caregiver	Unpaid informal caregiver
<p>Adult family members or other informal caregivers 18 years or older providing care to individual 60 years of age and older</p> <p>Grandparents and other relative caregivers 55 years of age or older providing care to children (under age 18 years) in the absence of parent(s) may receive services</p> <p>Grandparent or relative caregivers or informal caregiver, providing care for adult children with a disability, who are between 19 and 59 years of age, can be served under the NFCSP as follows:</p> <p>Parents must be 55 plus years of age caring for adult children with a disability, who are over 18 years of age</p> <p>Caregivers must be age 55 years and older (cannot be parent or step-parent of adult child unless that child has a disability and is 19 years and older)</p>	No specific age requirements for caregiver; care recipient must be 18+



Family Caregiver III-E	ADRD
No physician certification required	No physician certification required, but caregiver must confirm that care recipient's physician has made diagnosis of dementia
Care recipient requires assistance with at least 2 or more ADL's or has cognitive impairment to the point that he/she cannot be left alone	Care recipient has diagnosis of ADRD.
Includes both respite services and supplemental services(up to \$1000, supplemental expenses should not exceed 25% of site budget)	Includes respite services only
\$2000 (maximum) per year based on assessment Choice between agencies, family, friends or others as providers – must be hired as a "family managed employee"	\$1500 (maximum) per year based on assessment Choices between agencies, family, friends or others as providers - must be hired as a "family manages employee"

Financial Management Services

In addition to the ServiceLink sites, BEAS contracts with a Financial Management Services provider (FMS). The FMS contractor pays invoices and serves as the "Employer of Record" for individuals the family caregivers choose who to hire as respite providers (not employee of an agency), known as a "family managed employee". Under the nationally recognized model of Agency with Choice, the FMS conducts background checks, employee orientation, training, payroll processing, human resource functions, service unit reporting as required by the Administration on Aging, and customer service related to the financial services. Providing services as the "employer of record" for individuals chosen by the family caregivers as respite providers relieves the family caregiver of taking on the additional responsibility of providing payroll, workers' compensation liability, unemployment insurance and tax related issues, yet preserves their control over choosing and managing their respite providers

Documentation

Family caregivers who receive a budget for services paid for under Title III-E and ADRD should have the following documentation in their file:

1. Initial Assessment and any other follow up re-assessments if there has been a significant change in circumstances
2. Budget worksheet and plan plus all revisions. if applicable
3. Six month check check- in
4. Documentation of options presented to the family caregiver for their consideration



Title III-E & ADRD Program Questions and Answers

Grandparent / Relative Caregiver

Are grandchildren cared for by grandparents, required to have a disability or chronic illness (including those with mental retardation and developmental disabilities) in order to receive services?

There is no requirement that the grandchildren have a disability. Under the NFCSP, states may design services for grandparents or older individuals who are relative caregivers. In these instances, the grandparent or relative caregiver must be an older individual (55+), who lives with the child, is the primary caregiver of the child, and has a legal relationship to the child or is raising the child informally. The child must be no more than 18 years old.

Can respite and supplemental services be provided to grandparents and relative caregivers?

States have the option of using some portion of NFCSP funds (within the 10% statutory cap) to provide respite and supplemental services to grandparents and relative caregivers.

To allow grandparents a break from their daily caregiving responsibilities, funds under respite could be provided to pay expenses such as after school programs, summer/day camps, weekend programs and individual in-home respite. Supplemental funds could be provided to pay for expenses such as school supplies, legal issues associated with custody/adoption and other needs determined at the local level.

Can someone join as a Grandparent Caregiver if the parent is residing there but is not functioning as a parent?

A parent may be considered "absent" for several reasons such as drug use, illness, and mental health issues. Connect with BEAS NHCSP Manager to discuss per situation

Can a parent caring for their child received Title IIIIE grant?

Parent, 55 years and older caring for an adult child (18 years plus) with a disability are eligible to receive Title IIIIE grant. ONLY

If a child is 19 but has a disability and can remain in high school until 21 can they remain on the program?

Yes under Title IIIIE

If a Grandparent adopts the grandchildren can they remain in the program?

Yes, Grandparent who adopts their grandchild qualify for title IIIIE GP/Relative grant

Other

Does NHFCSP grant cash advances to caregivers?

No, NHFCSP does not grant cash advances to caregivers

Can caregivers use NHFCSP grants support caregivers so that he/she can work?



No. The Caregiver program's focus is to offer respite options to the caregiver....options that allow you , the family caregiver, to take a break from your caregiving responsibilities. The program is not meant to offer payment or coverage of care while the caregiver works.

Can a person living in the same household as caregiver get paid as direct service provider?

No, person related or not related living in the same household as caregiver cannot be paid as direct service provider.

Does the grant funds have to be included in taxes or be reported?

No, grant funds do not have to be reported on taxes as grants are not income for caregiver.

Do the grant funds have any influence my health insurance?

No, grant funds do not influence health insurance. However, if caregiver has full access to long-term care insurance policy that pays have for respite and care recipients' long-term care needs, they do not qualify to receive the grant. This is a case by case situation depends on their scope and availability of benefit.

Can I use hire someone to manage my grant and have that cost come out of my allotted funds?

No, the grant is for respite services and limited supplemental goods and services

Does the government and/or the state know all my information because I am using this grant?

No, the state nor the government knows all your information. Annual Federal reporting requires number of caregivers served and funds spent. Monthly, the FMS sends a report to the state with caregiver (name only) and status grant expenses.

If you have 2 care recipients (i.e. mother and father) and one caregiver can you have two grants?

No not for one caregiver. Start with the one grant and when money is spent we could possibly start another grant with alternate family caregiver who meets program criteria.

How to deal with a call from an agency who wants to know how much the caregiver grant is for – what can we say?

Provider agencies should not be informed of the amount of caregiver grant. This is confidential information and the caregiver has the right to change his/her mind as to what agency is used and what eligible goods and services are purchased.

How far may the care caregiver live from the care receiver and still be considered for the NHFCG program?

Caregivers receiving ADRD grants must live in the same household and be providing 24 hours care. The caregiver can live in the same building, right next door near enough to be able to respond to care recipient's needs 24/7.

Caregiver receiving Title IIIE grant must be providing at least 40 hours each week of care and live in close proximity.